

Approved 1-26-88
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by SENATOR ROY M. EHRLICH at
Chairperson

10:00 a.m./~~pm~~ on January 21, 1988 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Bill Wolff, Legislative Research
Norman Furse, Revisors Office
Clarene Wilms, Committee Secretary

Conferees appearing before the committee:

Wm. Svoboda, M.D., Medical Director, St. Francis Comprehensive Epilepsy
Center, Wichita
Michael J. Byington
REpresentative Jessie Branson
Senator Norma Daniels
Bertha McDowell, Executive Director of Epilepsy, Kansas
Cassie Lauver, Director, Crippled and Chronically Ill Childrens Program
Joan Strickler, Kansas Advocacy and Protective Services, Manhattan
Stephen Schiffelbein, Acting Commissioner for Kansas Rehabilitation
Services

Dr. William Svoboda testified supporting SB-461. This bill would allow a task force to address the need for services to the person involving not only the physician but the educator, the insurance field, the lawyer, law enforcement and others. Attachment 1

Michael Byington stated his support for SB-461. He also expressed a concern that some persons with epilepsy be included on the task force in order that the problems faced by people with epilepsy or other seizure related disorders be pointed out to the members of the task force. With many organizations treating only one aspect of the problem, there is no co-ordination involving the whole person. Attachment 2

Representative Jessie Branson spoke to the committee stating that she supported SB-461. She further stated that the issues of civil rights, insurance and public assistance for those with epilepsy and other seizure disorders needed to be addressed.

Senator Norma Daniels told the committee that as the interium committee worked on the issue of epilepsy and seizure disorders the picture continued to broaden until it became obvious a large segment of society needed attention. Problems range from diagnosis, expensive medication, inability to drive, learning difficulties, etc. The help available is very fragmented and little coordination between groups who do render service. More value could be received with an organized effort.

Bertha McDowell stated attempts have been made to coordinate with state officials. The establishment of a central organization is needed to gather and disburse information and helps from various sources. State officials have informed those working with epilepsy that a legislative mandate is needed and a task force established. Attachment 3

Cassie Lauver appeared before the committee stating the Kansas Department of Health and Environment supports SB- 461 which mandates

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 526-S, Statehouse, at 10:00 a.m./~~noon~~ on January 21, 1988.

study of the needs of epileptic individuals and individuals suffering from other seizure-related disorders, resources available to meet those needs and the coordination of available resources. In addition, it would result in comprehensive defining of multifaceted needs of this target population. Attachment 4

Joan Strickler stated that it makes sense to study and plan for the needs of people with epilepsy in order to obtain maximal human benefits per dollar expended. Attachment 5

Stephen Schiffelbein appeared before the committee and testified in favor of the creation of the task force proposed in SB-461. He further stated that this would be an effective means to determine how to meet the needs of Kansans on a statewide level. Attachment 6

The meeting adjourned at 10:53 a.m. and will meet January 22, 1988.

SENATE
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE January 21, 1988

(PLEASE PRINT)
NAME AND ADDRESS

ORGANIZATION

Gary K. Hulet		KS DEPT. HEALTH & ENVIRONMENT
Cezil Young		KDHE
Cassie Lawrence		KDHE
Monty Grant		"
Stephen Schiffelken		SRS - Rehab Services
Marilyn Bradt		KINH
KEITH R LANDIS		CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS
JOE A. MORRIS	Topeka	KLSI
Cathy Lynn		
Bob Perkins		Kansas Hospital Assn.
SHELBY SMITH	Wichita	Stawson Companies
Nanna Danjoh		Senator
William B. Koloda MD	Wichita	Prof. Neurology, Wash. Univ. School of Med.
Brytha McDowell	Wichita	Epilepsy - Kansas
John Strutt		KAPS
Rep. Jessie Branson		Leg

TESTIMONY ON SENATE BILL NO. 461 PROPOSAL NO. 30

William B. Svoboda, MD, Pediatric Neurology
Medical Director, Institute of Logopedics
Medical Director, St. Francis Comprehensive Epilepsy Center
Chairman, Epilepsy Kansas Professional Advisory Board

I. GENERAL IMPORTANCE OF TASK FORCE:

The bill you today consider offers people with epilepsy a chance for a modern present and a better future,...a future in which they can escape the welfare cycle to become achieving children and employed adults.

II. EXAMPLE OF NEED:

You may ask....is this really needed? Consider:

A newborn suffers damage from avoidable, yet unrecognized seizures; the baby in the next crib is over-diagnosed as epileptic and lies over-medicated.

A preschool child experiences one of the epileptic mixed syndromes with other handicaps including retardation. Needed pre-school services are lacking. Seizures may render such help unaccessable.

A family cannot obtain financial assistance for their epileptic child. They cannot get insurance. The diagnosis of a tumor excludes them from Crippled Children's services. The local Health Maintenance Organization refuses to refer them for needed care.

A child fails in school. The school blames the epilepsy and the drugs. The child receives no help for the learning difficulties. The family is told that it may be best that the child remain at home, lest he disturb the class with his seizures.

A young lady is thought possibly to have seizures. Thus she is sterilized.

A man with epilepsy is employed until the diagnosis is discovered. He loses his job. He cannot obtain another job because he cannot drive to work.

These are typical horror stories, composites of what we hear daily.....samples of needs unserved.

(2)

In this group here today, 1 of every 9 of you will experience a seizure sometime in your lifetime.....and with luck, you may receive adequate care.

One of every 50 of your constituents has or will develop epilepsy.

Half of the epileptic children will have trouble learning.

Half of all epileptic people are handicapped by major, unmet, mental health needs.

Half of all adults are either unemployed or under-employed, and thus often on welfare.

And if your constituent is a member of a minority group, the outlook is even worse. He is more apt to have epilepsy, more apt to suffer other problems, yet less apt to be helped by existing services.

II. OTHER STATES WITH TASK FORCES:

In the mid-70s, the Federal Commission on Epilepsy identified needs, services, and approaches that can and should be developed on national, state, and local levels.

A National Plan of Action was developed, giving us a framework of questions to ask, programs to plan, and approaches to initiate , all toward completing a state plan.

A. Experiences of other states:

Over the next decade, state after state after state has come forth with plans and resultant programs.

An entire different picture of epilepsy and it's management is emerging. For ages, epilepsy has been associated with demons and dread, mysticism and magic, idiocy and insanity. Now, epilepsy is more than pill pushing, it is a problem of language and learning, of emotions and earning.

Modern treatment must address the whole person. No longer is epilepsy ~~no~~ the exclusive domain of the doctor. Now it is a challenge to the educator and the employer, the insurer and the insured, the lawyer and the lawman, and to many, many others.

B. The Benefits Realized:

If the proposed Task Force does no more than to identify needs and services, it would be as major breakthrough. But this approach has been so structured that it can provide a model of cooperative, collaborative, comprehensive care....a framework which can stimulate similar services to other developmental disabilities.

This Task Force may open up a pandora's box of problems, but it also can provide solutions.

This Task Force will uncover resources unknown to most in need and thus will link consumer with provider

This Task Force can open the eyes of many agencies, resulting in new collaborations for the good of all.

What this Task Force can become is up to you. The Task Force must be appointed with care and concern:

- 1) Those serving should be knowledgeable or at least willing to learn.
- 2) Those appointed should be creative, yet also cost concerned.
- 3) Those involved should be collaborative as well as cooperative.
- 4) Those participating, must be willing to provide needed leadership, both during and afterward.

The Task Force must be dedicated to developing:

- 1) An effective, economical, efficient plan
- 2) Including a means and method of activation,
- 3) Identifying both potential providers and costs thereof.

At the end of this year, you should expect

- 1) Documented facts supporting the needs
- 2) Designated services already existant
- 3) Designed methods for improving services that are reasonable, attainable, and economical.

This can be the start of a modern day for those with epilepsy in Kansas, who, along with those in other states and nations, can make this great leap forward.

January 21, 1988

TO: Senate Committee on Public Health and Welfare

FROM: Michael J. Byington, Registered Lobby
Epilepsy, Kansas

SUBJECT: Senate Bill 461

I was pleased to have an opportunity to address some of the needs of persons having epilepsy and other seizure related disorders in some depth during the interim consideration of Proposal #30. I now come forward in support of S461.

While I do some voluntary lobbying for Epilepsy - Kansas Inc., I speak here more as a service provider attempting to case manage, and sometimes provide directly, human services to persons having epilepsy or other seizure related disorders. I do these things through my employment as the Advocacy Coordinator for the Topeka Resource Center for the Handicapped.

This bill marks a beginning. Interim studies often result in the conclusion that yet more study is necessary, and this is apparently what happened in the case of this study and subsequent introduction of this bill. The question now to be addressed is that of why it is so important to study this issue, and why it is necessary to develop a special task force just to do so. The answer is found in looking at the State human services structure. There are for almost all other disability groups, specialized human service sections assigned duties with reference to serving and researching services relating to the specific disability in question. Within Rehabilitation Services of S.R.S., there is a special Division of Services for the Blind and a Commission for the Deaf and Hearing Impaired. S.R.S. also has an entire Division committed to serving person having mental health and/or mental retardation problems. Yet another S.R.S. Division is committed specifically to serving persons having drug and/or alcohol problems. Despite these specializations, there is no special unit, no nitch, to address the problems of persons having epilepsy or other seizure related disorders. This results in a situation where information, case management, and service coordination are extremely difficult to bring together.

Epilepsy is a severe problem. Although certainly some wonderful medical breakthroughs have taken place, many persons having epilepsy can not fully control seizures via medication and treatment. These individuals generally have very unstable employment histories and increased hospitalization.

The proposed task force will not answer any of the concerns listed above. It may, however, be a beginning. It warrants your support and favorable action.

My only concern about the bill is that I certainly feel that a significant number of individuals on the task force should be persons having epilepsy or other seizure related disorders. I am surprised that the bill is not specific to this requirement, but careful appointments should assure a good task force with an adequate number of persons having epilepsy or other seizure related disorders.

Testimony Before the Senate Committee On Public Health and Welfare
by Bertha McDowall, Executive Director of Epilepsy-Kansas
Topeka, Kansas January 21, 1988

Mr. Chairman and members of the Committee On Public Health and Welfare, I want to thank you for the opportunity to address you today. My name is Bertha McDowall and I am the Executive Director of Epilepsy-Kansas, the State affiliate of the Epilepsy Foundation of America. I am here to help advocate for the 1% of adults and 2% of children in this state who have epilepsy.

Since Epilepsy-Kansas was incorporated in 1972, our staff has been in contact with many individuals, family members, friends, employers and concerned others personally facing the challenges presented by epilepsy. On the average, we receive 65 calls a month for information, referral, support, advocacy and employment help. This volume is without extensive outreach so the need is probably much greater.

In the time I have been with Epilepsy-Kansas, I have noticed that there are very few calls just asking for medical information alone. Usually, one area of concern leads to another and most relate to even other areas in the past. It does not take very long for an "intake" worker to discover that, for instance, what was a "simple" employment related question really is a mental health, education, transportation and/or other problem also. It is then that the individual with epilepsy faces head on the problems of finding the appropriate services and coordinating the services offered.

The sad fact is that this is the point that we either lose or almost adopt many people. I am sure you have experienced at some point being referred around in circles only to be more confused than ever with the end result of just giving up on the particular issue. This is not an uncommon occurrence

for people with epilepsy when they try to determine just who can help them and how. It is also not an uncommon occurrence for some of these people to just give up - medication compliance, drive and self-esteem abandoned.

At the other extreme, are the individuals that you deal with year after year as they go through the maze of services while their situation gets worse. During that time they are consuming resources in the form of public assistance of one sort or another when instead they could be contributing members of society. What happens next can be more extensive medical bills and unemployment costs which are, of course, passed along to the general public.

Let me give you an example of what is happening.

We have been dealing with one man for at least 4 years. He has been dealing with Vocational Rehabilitation for much of that time. He has been tested and re-tested, still he does not have a job and does not really know what the next steps for him are. His medications are having an effect on his ability to work, but no one is working with him to solve this problem. In the meantime, he has developed a self-esteem problem because he doesn't understand what is happening to him as he goes from one agency to the other. In the meantime, the people involved with him in each agency wonder why the other people cannot solve his problem. What they may not realize is that they are all dealing with different problems without knowing the overall effects. As a result, this person is still waiting - on public support, having used hours of agency time with little to show for it.

In an effort to be more effective in guiding people who call us to appropriate sources of assistance, our staff and that of the Greater Kansas City Epilepsy League began to meet with various state department heads. Our hope was to determine just who was offering what services to whom and what efforts were

being made to coordinate them. Although the people we met were helpful and sympathetic, they stated time and again that there was no vehicle to currently coordinate services and without a "Legislative Mandate" they could not readily furnish the information we requested given their current budget and staffing constraints - the legislature would have to make it a priority. We are now looking to the members of this committee to help make this possible.

A task force is a very important step in making services for people with epilepsy available and more effective. A statewide study should be conducted to determine the needs of this population, the services available currently and gaps in service. Furthermore, there should be a plan of action to address identified needs and a vehicle determined which would coordinate existing and future services.

Human lives are a precious asset to waste and increasingly scarce human service dollars need to be conserved and spent effectively. We urge you to support this bill that would enable the at least 29,000 people in Kansas with epilepsy to lead more independent and productive lives.

Thank you.

Testimony Presented to
Senate Public Health and Welfare Committee

by

The Kansas Department of Health and Environment

SB 461

Services provided to the residents of Kansas under twenty-one years of age through Crippled and Chronically Ill Children's Program (CCICP) focus on prior authorized medical specialty services for those with handicaps. Diagnostic services are available for any individual under the age of twenty-one suspected to have a severe handicap, disability or chronic disease. Treatment services are limited to those individuals with a medically eligible condition and whose families meet the financial guidelines of the program. The medically eligible conditions, method used to determine financial eligibility and other information pertaining to the program activities are found in KAR 28-4-400 through 28-4-408. At this time, the diagnosis of seizures, is medically eligible through CCICP.

Seizures were added to the list of medically eligible conditions in the CCICP program in 1978, but were deleted in 1980 because the budget was insufficient to absorb the cost associated with this coverage. The 1984 legislature appropriated \$30,000 to reinstate seizure services and determine the future need. Legislative intent was that a pediatric seizure clinic be established in Wichita to augment the existing services in Kansas City. In FY 85, additional services were made available. These services included laboratory tests, x rays and medications.

A multidisciplinary team consisting of a pediatric neurologist, psychologist and nurse/coordinator began seeing patients at the University of Kansas School of Medicine-Wichita in December, 1984. Several meetings were held with members of the health care delivery team in Wichita to establish a permanent place for a multidisciplinary clinic. These meetings culminated in the rejection of a contract by St Francis Regional Medical Center in December, 1985. Beginning in the summer of 1986, the multidisciplinary clinic site was transferred to Dr William Svoboda's private office in Wichita. This clinic is currently held one-half day per month. Payment is made to the team members using a fee per clinic day and to Dr Svoboda for management of the clinic. Other services are available as needed to meet the needs of the individual. Professionals, other than the team members, are paid on a fee for service basis.

In Kansas City, a contract was developed to provide a multidisciplinary clinic which meets two half days per month. The professionals in the clinic include a pediatric neurologist, counselor/educator, social worker and clinic coordinator. Other services are available as needed to meet the needs of the individual. Professionals, other than the team members, are paid on a fee for service basis.

The following table shows the increase in expenditures for the seizure program from FY 85 to FY 87. Factors contributing to the increase in the average amount paid per child included the increased use of magnetic resonance

SB 461

resonance imaging, increase in medical care costs, coverage of medications in FY 86 and FY 87 and the increase in the number of children without any other third-party payment source.

	FY 85	FY 86	FY 87
Unduplicated number of children	207	269	355
Total amount of dollars spent	\$9,550	\$31,008	\$44,596
Average amount per child	\$46	\$115	\$125

The Kansas Department of Health and Environment supports this bill which mandates the study of the needs of epileptic individuals and individuals suffering from other seizure-related disorders, resources available to meet these needs and the coordination of available resources. The result of this study would go beyond the medical needs aspect by comprehensively defining the multifaceted needs of this target population. Additionally, it would plan for future coordination and collaboration between the organizations and state agencies delivering a variety of services to and otherwise affecting the lives of individuals with epilepsy and seizure-related disorders.

Testimony presented by Cassie Lauver, ACSW, Director
Crippled and Chronically Ill Children's Program
Kansas Department of Health and Environment

Kansas Advocacy & Protective Services, Inc.



Suite 2, the Denholm Bldg.
513 Leavenworth
Manhattan, KS 66502
(913) 776-1541

Chairperson
R. C. (Pete) Loux
Wichita

TO: The Senate Committee on Public Health and
Welfare
Senator Roy Ehrlich, Chairperson

Vice Chairperson
Robert Anderson
Ottawa

FROM: Kansas Advocacy and Protective Services, Inc.,
R.C. Loux, Chairperson

Secretary
Neil Benson
El Dorado

RE: SB 461

DATE: January 21, 1988

Treasurer
Robert Epps
Topeka

Rep. Rochelle Chronister
Neodesha

Sen. Norma Daniels
Valley Center

Sen. Ross O. Doyen
Concordia

Harold James
Hugoton

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Topeka

W. Patrick Russell
Topeka

Rep. Jack Shriver
Arkansas City

Raymond L. Spring
Topeka

W. H. Weber
Topeka

Liaison to the Governor
Jose A. de la Torre

Executive Director
Joan Strickler

KAPS assists children and adults with disabilities in gaining access to the rights and services to which they are entitled. We administer two federal programs—protection and advocacy as provided for by the Developmental Disabilities Act (PL 94-103 as amended) and the Protection and Advocacy for Mentally Ill Individuals Act (PL 99-319). We also administer the Kansas Guardianship Program, a program funded by and unique to Kansas. KAPS is a private non-profit corporation with authority to pursue legal, administrative and other appropriate remedies on behalf of the persons it serves. There are 56 similar agencies serving our states and territories.

At its meeting last March, our Governing Board took a position that Kansas should study, in depth, the issues related to the needs of mentally ill, mentally retarded, developmentally disabled and all Kansans with severely disabling conditions. The Board noted that it was time for Kansas to develop policies and to make long range plans to guide us now and decades to come.

In its position paper KAPS suggests that existing programs in Kansas and other states be examined and that attention also be given to looking at innovative approaches to meeting needs. Such approaches might include:

- Investigating possible use of existing technology or developing new technology to assist disabled persons to lead more independent lives i.e. rehabilitation engineering.

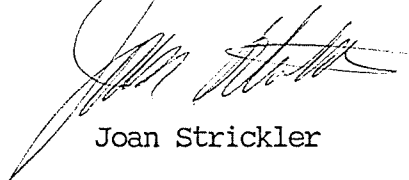
KAPS has been charged with developing systems of advocacy and protective services in Kansas relevant to the provisions of Sec. 113 of P.L. 94-103, as amended; the Developmental Disabilities Services and Facilities Construction Act, and P.L. 99-319, the Protection and Advocacy for Mentally Ill Individuals Act.

Senate Public Health & Welfare
January 21, 1988
Attachment 5

- Considering volunteerism as it has successfully been implemented through Vista and the Kansas Guardianship Program.
- Pursuing cooperative relationships and shared responsibilities involving the states, local governments, private business, churches and charitable organizations.

SB 461, which would create a 12 member task force on epilepsy and other seizure related disorders, could provide information and recommendations targeted toward the unique needs of that specific population of Kansans with disabilities. As the State addresses the needs of persons with epilepsy and other seizure conditions, and the needs of all persons with severely disabling conditions, it makes sense to study and plan for those needs in ways that will strive for maximal human benefit per dollar expended.

Respectfully submitted,



Joan Strickler

**State Department of Social and Rehabilitation Services
Testimony in Support of SB 461**

Rehabilitation Services supports establishment of a task force to study the needs of persons with epilepsy and other seizure-related disorders.

Kansans with epilepsy represent a willing pool of workers who can contribute to the work place and the communities in which they live--if given the opportunity. Rehabilitation Services provides counseling, training and services to help these Kansans achieve employment and independence. However, statistics from Epilepsy Kansas, Inc., indicate that about 25% of persons with epilepsy are unemployed and another 25% are under-employed.

Work opportunities for persons with disabilities often do not exist because employers misunderstand or fear the effects of a disability. When a person with a disability, such as epilepsy, applies for a job, these misunderstandings can prevent the employer from seeing the person's true work abilities. Greater public awareness and education, which would result from the work of the proposed task force, would help combat these myths and misunderstandings that keep qualified workers from employment.

Identification of available resources and plans for meeting the needs of persons with epilepsy, through the proposed task force, would also benefit the work of Rehabilitation Services. The availability of such information would be useful to:

- * Vocational rehabilitation counselors in developing appropriate rehabilitation plans for individual clients.
- * The agency in developing plans and setting priorities for services.

At public forums held in 1987 by Rehabilitation Services, representatives of a statewide consumer group also noted the need for:

- * A comprehensive network to exchange medical, educational, mental health and vocational information for persons with epilepsy.
- * Vocational preparation and assistance for adolescents with epilepsy in transition from school to adult life.

The proposed task force would be an effective means to determine how to meet these needs on a statewide level.

The creation of this proposed task force would benefit the Kansans we serve through vocational rehabilitation. Therefore, I pledge our cooperation should the task force be created, and urge your support of Senate Bill 461.

Stephen Schifflbein
Acting Commissioner
Rehabilitation Services
State Department of Social and
Rehabilitation Services
296-3911
January 21, 1988